



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

**ACTION:** Notice.

**SUMMARY:** In accordance with the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) has scheduled a public meeting. Information about ACHDNC and the agenda for this meeting can be found on the ACHDNC website at: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** September 24, 2019, 10:00 a.m. - 1:00 p.m. Eastern Time (ET).

**ADDRESSES:** This meeting will be held via webinar. While this meeting is open to the public, advance registration is required. Please visit the ACHDNC website for information on registration: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. The deadline for online registration is 12:00 p.m. ET on September 23, 2019. Instructions on how to access the meeting via webcast will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau (MCHB), HRSA, 5600 Fishers Lane, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of HHS (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. ACHDNC's recommendations regarding inclusion of additional conditions for screening, following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA through the Recommended Uniform Screening Panel (RUSP) pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the September meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include a discussion of the role of health information technology within state newborn screening programs and general updates on ACHDNC projects focused on newborn screening. Agenda items are subject to changes as priorities dictate and the final meeting agenda will be available on ACHDNC's website: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Information about the ACHDNC, a roster of members, as well as past meeting summaries are also available on the ACHDNC website.

Members of the public will have the opportunity to provide comments. Requests to offer oral comments will be accepted in the order they are requested and may be limited as time allows. Public participants may also submit written statements. To submit written comments or request

time for an oral comment at the meeting, please register online by 12:00 p.m. ET on September 19, 2019. Visit the ACHDNC website for information on registration, <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Oral comments will be honored in the order they are requested and may be limited as time allows. Individuals associated with groups or who plan to provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted. Written comments should identify the individual's name, address, email, telephone number, professional or organization affiliation, background or area of expertise (i.e., parent, family member, researcher, clinician, public health, etc.) and the topic/subject matter.

**Maria G. Button,**

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